July 5, 2016 Last Updated: July 5, 2016

# User Guide for Medical Educators

# Bioethics Commission Educational Materials

The Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) has developed educational materials for use in traditional and nontraditional educational settings to provide educators with contemporary examples of real-life ethical challenges addressed by a presidential commission. The materials are designed to be applicable to a wide variety of disciplines at the undergraduate, graduate, and professional levels as well as continuing education and professional training courses, graduate or professional school seminars, workplace discussions, and other settings.

The purpose of this guide is to highlight the most relevant materials for educators in medicine and the health sciences. This list is not exhaustive; rather, it is meant to serve as a quick reference to some of the most relevant materials.

The webinar <u>Multidisciplinary Implementation of Bioethics Commission Education Materials</u> demonstrates how topic-based modules can be employed in various disciplines, including medicine.

# **Incidental Findings**

Various diagnostic tests and procedures, including imaging and genetic testing—whether conducted in the clinical, research, or direct to consumer contexts—can lead to the discovery of incidental or secondary findings. Medical educators can guide students and professionals in understanding incidental and secondary findings and discussing how to handle such findings during the course of research and when interacting with patients. Two primers written for <u>patients</u> and for <u>clinicians</u> can help medical and health professions students understand incidental and secondary findings from multiple perspectives.

Instructors can also engage students in an active learning exercise with the <u>Deliberative Scenario: Law Enforcement Access to a Genetic Database</u>, which guides students through the ethical scenario in addition to a deliberative process to reach consensus about how to address the issue. The scenario also comes with a teacher companion.

#### Genetics

Genetics instructors covering large-scale genomic sequencing technologies might engage students in discussions related to ethical concerns and question, including informed consent processes and privacy protections for individuals when their whole genome sequence data are used for research. The <u>Informed Consent in Privacy and Progress</u> module provides information and analysis about informed consent processes in the context of whole genome sequencing, and the <u>Privacy and Progress</u> module addresses the importance of privacy in whole genome sequencing, and the inherent tension between protecting individuals' privacy and supporting the progress of promising genomic research.

#### Neuroscience

Instructors covering neuroscience might discuss ethical issues related to contemporary neuroscience. The <u>Classroom Guide on Ethics and Neuroscience</u> outlines ethical issues related to cognitive enhancement, consent capacity, and neuroscience and the legal system. The primer <u>For Researchers: Neuroscience and Consent Capacity</u> describes how consent capacity might be affected in patients with certain neurodegenerative conditions, and is a relevant topic in both research and clinical care.

Instructors can also engage students in a more active learning exercise with the <u>Deliberative Scenario</u>: The Use of Prescription Stimulants for Enhanced Academic Performance, which guides students through

July 5, 2016 Last Updated: July 5, 2016

the ethical scenario in addition to a deliberative process to reach consensus about how to address the issue. The scenario also comes with a teacher companion.

#### **Clinical Research**

Medical professionals often conduct or refer patients to clinical research, and medical educators can begin discussing ethical issues relevant to clinical research early in a clinician's career. The Research Design Background module provides general information about ethical research design—including types of research, research risk, sample size, data collection and analysis, sharing of results, and validity and related concepts—and examples specific to clinical and public health research. It provides information on some of the regulatory requirements for research, including responsible conduct of research standards and protection of research participants. Class discussion about clinical trials and public health research also might include consideration of such topics as informed consent and vulnerable populations in research.

The Informed Consent Background module describes the ethical underpinnings of informed consent, the history of informed consent for research and how it came to be regulated in the United States, and common implementation challenges in the informed consent process. Other modules provide examples, information, and analysis about informed consent processes in such contexts as whole genome sequencing (Informed Consent in *Privacy and Progress*), pediatric medical countermeasure research (Informed Consent in *Safeguarding Children*), research or other activities that could result in incidental and secondary findings (Informed Consent in *Anticipate and Communicate*), and neuroscience research that involves participants with who have or might develop impaired consent capacity (Informed Consent in *Gray Matters*).

Discussion about clinical research might include various conceptions of vulnerability and examples of vulnerable populations that are outlined in the <a href="Vulnerable Populations Background">Vulnerable Populations Background</a> module, in addition to applicable regulations, guidelines, and related protections for vulnerable populations. The <a href="Study Guide to">Study Guide to</a> "Ethically Impossible" provides a historical case study based on research conducted by U.S. Public Health Service personnel in Guatemala involving the intentional exposure of vulnerable populations to sexually transmitted diseases without their consent. The <a href="Vulnerable Populations in Safeguarding Children">Vulnerable Populations in Safeguarding Children</a> module addresses children as a vulnerable population generally and within the context of medical countermeasure research specifically. In addition, the <a href="Vulnerable Populations in Gray Matters">Vulnerable Populations in Gray Matters</a> module addresses potentially vulnerable groups that might participate in neuroscience research, such as individuals who have or might develop impaired consent capacity.

#### **Public Health**

Physicians often are actively involved in communicating public health information to their patients and to the public. Medical educators might begin discussing how to effectively approach ethical challenges that might arise during public health emergencies. The <u>Classroom Discussion Guide on Ethics and Public Health Emergencies</u> provides structured questions to guide group discussion about ethical challenges that can arise during public health emergencies, focusing in particular on the recent Ebola virus disease epidemic in western Africa. In addition, the collection of <u>Public Health Case Studies</u> provides contemporary and relevant case studies that address ethical implications of public health practice and research.

## **Community Engagement**

Medical practice often involves extensive community engagement, and students in health professional programs often play a key role in shaping community engagement efforts. The <u>Community Engagement Background</u> module outlines various approaches to, ethical reasoning behind, and challenges to community engagement. The <u>Community Engagement in Moral Science</u> module builds upon the content of the background module to address how community engagement fits into other aspects of human subjects research, and considers community engagement in both domestic and international contexts.

Last Updated: July 5, 2016

## **New and Emerging Biotechnology**

New and emerging technologies, such as synthetic biology and large-scale genomic sequencing, have the potential to promote the health of populations, and physicians play a key role in communicating advances to patients. Community engagement is an important way for scientists and others to educate the public about new technologies and understand the concerns that affected communities might have about the development and use of those technologies. The Community Engagement in New Directions module illustrates the importance of public and community engagement for research on emerging technologies including synthetic biology to provide opportunities for members of the public, researchers, and policymakers to share concerns, learn from each other, and work together to support safe and productive research. In addition, the Community Engagement in Privacy and Progress module considers how community engagement applies in the context of large-scale genomic sequencing data, including storage and use. The Privacy in Privacy and Progress module addresses the importance of privacy in large-scale genomic sequencing, and the inherent tension between privacy and supporting the progress of promising genomic research.